

The End at the Beginning

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ABSTRACT

The clinical management of infants born with disabilities and at the cusp of viability has been a focus of attention in recent years because of medical advances as well as legislative activity. This article looks at the history, in terms of law and medical tradition, of this issue as well as how healthcare providers have been and could be affected.

Few revolutions begin in Indiana, yet the controversy surrounding the birth and death of the unidentified infant now known as Baby Doe—born April 9, 1982, in Bloomington, Indiana—continues to resonate in the management of infants born with disabilities. The regulations resulting from this case now insert themselves into all decisions regarding management of newborn infants, particularly those decisions made for infants born at the cusp of viability.

BABY DOE

Historically, government authority has avoided intrusion into the sphere of influence surrounding the perceived right of the family in consultation with physicians to make decisions regarding the care of their child. All this changed when the obstetrician delivering a child born with Down syndrome and tracheoesophageal fistula recommended that the family not pursue treatment, citing a 50% chance of surviving surgical repair and bleak prospects if the child survived. Advised of the family's decision not to provide consent

for repair of the tracheoesophageal fistula, the family physician and a local pediatrician strongly opposed this plan. Their concern stemmed from their belief that the prognosis for a good medical outcome after surgical repair of an abnormal esophagus based on contemporary management was much more favorable than the family was led to believe. These physicians enrolled several attorneys and enlisted couples willing to adopt the child in an effort to prevent the child's imminent death. The case was presented to local courts, appealing for a declaration of neglect under Indiana's Child in Need of Services statute. The courts chose to follow contemporary precedent, deferring to the parents' decision. The case was then prepared for presentation to U.S. Supreme Court Justice John Paul Stevens. Baby Doe died of dehydration and pneumonia at 6 days of age on April 15, before the case could be heard.¹

Upon learning of the case of Baby Doe, U.S. Surgeon General C. Everett Koop was outraged. His opinion was driven by conservative Christian ideals and his own experience of nearly 100% success with the repair of tracheoesophageal fistulas while Surgeon in Chief at the Children's Hospital of Philadelphia. He opined that the decision to forego treatment could only be based on discrimination because of the diagnosis of Down syndrome and the family's concern for future disability related to this diagnosis. Koop began a campaign to prevent this perceived discrimination against children with disabilities leading to the withholding of medical intervention. After he enlisted the resources of the Reagan administration, controversial rules were soon in place, promulgated under the Americans With Disabilities Act to prevent such perceived abuses.¹

Citing "heightened public concern" in the aftermath of the Baby Doe incident, on May 18, 1982, the director of the Department's Office of Civil Rights, in response to a directive from the President, "remind[ed]" healthcare providers receiving federal financial assistance that newborn infants with handicaps such as Down syndrome were protected by the Americans With Disabilities Act.² This notice was followed on March 7, 1983, by an Interim Final Rule contemplating a "vigorous federal role" for the enforcement of these rules.³

This initial effort to prevent the perceived withholding of care from handicapped infants solely on the

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basis of their disability included the creation of Baby Doe Hotlines and federally mandated posting of notices in all hospital nurseries that included the instruction “Any person having knowledge that a handicapped infant is being discriminatorily denied food or customary medical care should immediately contact: Handicapped Infant Hotline” and a telephone number for the US Department of Health and Human Services (HHS).⁴

BABY JANE DOE

Surgeon General Koop soon found an appropriate forum for voicing his concerns after the birth of a child diagnosed with spina bifida, microcephaly, and hydrocephalus in Port Jefferson, Long Island, on October, 15, 1983.¹ The infant, known as Baby Jane Doe, was promptly transferred to Stony Brook Medical Center for medical management, where the parents decided against intervention after receiving contradictory medical opinions. HHS became involved in this case after a Baby Doe Hotline call reported concerns regarding the withholding of treatment, spurring Koop into action.⁴ Subsequent unsuccessful efforts to subpoena medical records and compel medical intervention through court action are well documented.

Meanwhile, several professional organizations challenged the regulations mandating the creation of the Baby Doe Hotlines, reaching the courts as *Bowen vs American Hospital Association*.³ In 1986, the US Supreme Court struck down the first rules establishing the Baby Doe Hotlines under the Americans With Disabilities Act.

BABY DOE RULES

Despite the setback of the court decision regarding the initial regulations promulgated under the Americans With Disabilities Act, the efforts of Koop and the Reagan administration continued. The results of these efforts are known as the Baby Doe Rules, which survived congressional review as part of the 1988 Revision of the Child Abuse Prevention and Treatment Act (CAPTA).⁵

This act includes the following provisions:

The term “withholding of medically indicated treatment” means the failure to respond to the infant’s life-threatening conditions by providing treatment (including appropriate nutrition, hydration, and medication) which, in the treating physician’s (or physicians’) reasonable medical judgment, will be most likely to be effective in ameliorating or correcting all such conditions, except that the term does not include the failure to provide treatment (other than appropriate

nutrition, hydration, or medication) to an infant when, in the treating physician’s (or physicians’) reasonable medical judgment any of the following circumstances apply:

- (i) The infant is chronically and irreversibly comatose;
- (ii) The provision of such treatment would merely prolong dying, not be effective in ameliorating or correcting all of the infant’s life-threatening conditions, or otherwise be futile in terms of the survival of the infant; or
- (iii) The provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane.

These rules seem unequivocal, and as recently as 2004, Robertson⁶ claimed that any controversy surrounding the Baby Doe rules is dead and that the rules are absolute. He argued that the regulations leave no room for interpretation and include no allowance for parental concerns. He followed by examining the difficulties this interpretation imposes for families and caretakers when faced with the prospect of an infant likely to require lifelong care with little or no meaningful interaction with the environment.

QUALITY OF LIFE: THE OPPOSING VIEW?

The Baby Doe rules appear to allow little room for interpretation. They seem to unequivocally restrict the ability of families and physicians to incorporate quality-of-life considerations when making decisions for an infant, which most authorities continue to accept as *the* standard of care. The American Medical Association formally endorsed the quality-of-life standard prior to the Baby Doe case, as summarized by this statement:

In the making of decisions for the treatment of seriously deformed newborns or persons who are severely deteriorated victims of injury, illness, or advanced age, quality of life is a factor to be considered in determining what is best for the individual.

In caring for defective infants the advice and judgment of the physician should be readily available, but the decision as to whether to treat a severely defective infant and exert maximal efforts to sustain life should be the choice of the parents. The parents should be told the options, expected benefits, risks, and limits of any proposed care; how the potential for human relationship is affected by the infant’s condition; and relevant information and answers to their questions.⁷

THE BEST INTERESTS STANDARD

Paradoxically, the position that parents and physicians should make all decisions for infants was also supported by the contemporaneous recommendations of the President's Commission for the Study of Ethical Problems in Medicine, first outlined in its 1982 report "Making Health Care Decisions."⁸ This document from Reagan's own appointees, selected to provide guidance on ethical issues during his tenure, reviewed the process of guidance in making decisions for those unable to speak for themselves. In cases where the patient is unable to participate in the medical decision-making process and there is no previous history to provide insight into how the incapacitated person might wish to proceed, the commission supported the concept of the best interests standard:

Decisionmaking guided by the best interests standard requires a surrogate to do what, from an objective standpoint, appears to promote a patient's good without reference to the patient's actual or supposed preferences. This does not mean the surrogate must choose the means the practitioner thinks is "best" for promoting the patient's well-being, but only a means reasonably likely to achieve that goal.⁸

This concern was addressed specifically for end-of-life decisions the following year in the commission's report "Deciding to Forego Life-Sustaining Treatment."⁹ This report stated that surrogate decisions made when the patient is incapable of making his or her own decisions for any reason should first rely on the concept of substituted judgment where the "standard requires that a surrogate attempt to reach the decision that the incapacitated person would make if he or she were able to choose." The report noted that the appropriate means of decisionmaking should rely first on any previously cited preferences of the now-incapacitated patient. The commission considered circumstances in which "some patients have never been competent; thus, their subjective wishes, real or hypothetical, are impossible to discern with any certainty" and invoked the best interests standard for this situation that best describes the circumstance of a parent making decisions for a newborn infant. "In these situations, surrogate decision makers will be unable to make a valid substituted judgment; instead, they must try to make a choice for the patient that seeks to implement what is in that person's best interests by reference to more objective, societally shared criteria."⁹

The commission specifically cited factors such as "relief of suffering, the preservation or restoration of functioning, and the quality as well as the extent of life

sustained" and stated that the "impact of a decision on an incapacitated patient's loved ones may be taken into account in determining someone's best interests, for most people do have an important interest in the well-being of their families or close associates."⁸

This same report directly addressed the decision-making process for critically ill neonates. "Parents should be the surrogates for a seriously ill newborn unless they are disqualified by decision-making incapacity, an unresolvable disagreement between them, or their choice of a course of action that is clearly against the infant's best interests."⁹ Recognizing the contemporaneous concern regarding Baby Doe, commission members also noted, "infants should receive all therapies that are clearly beneficial to them. For example, an otherwise healthy Down syndrome child whose life is threatened by a surgically correctable complication should receive the surgery because he or she would clearly benefit from it."⁹

ENSURING ETHICAL DECISIONS

After identifying the parents as the appropriate surrogate decisionmaker in almost all circumstances, the commission commented on the importance of appropriate information as the basis for making decisions and the responsibility of physicians: "Decisionmakers should have access to the most accurate and up-to-date information as they consider individual cases." This statement recognizes that controversial decisions sometimes reflect information that is not up to date or complete, as implied in the case of Baby Doe when the information that led to the decision to withhold permission to repair the esophageal atresia was provided by the presumptively less informed obstetrician. To ensure that decisions to forego therapy are approached in a consistent fashion, the commission recommended that a committee be created within each institution providing care for infants and be tasked with the review of all decisions to forego therapy or cases in which opinions regarding appropriate care might diverge. Commissioners emphasized the need for institutional introspection into this process, recommending not only prospective evaluation when issues arise, but also a formal process for "retrospective review of decisions when life-sustaining treatment for an infant might be foregone or when parents and providers disagree about the correct decision for an infant. Certain categories of clearly futile therapies could be explicitly excluded from review."⁹

The commission also recognized the potential for controversy regarding appropriate care of an ill neonate and suggested the following guidance: "The best interests of an infant should be pursued when

those interests are clear. The policies should allow for the exercise of parental discretion when a child's interests are ambiguous."⁹ The commission also acknowledged the necessary roles of the law and judicial intervention: "Decisions should be referred to public agencies (including courts) for review when necessary to determine whether parents should be disqualified as decisionmakers and, if so, who should decide the course of treatment that would be in the best interests of their child."⁹

Finally, the commission directly addressed the role of government in surrogate decisions for newborns, appearing to rebuke the efforts by the Reagan administration to regulate neonatal decisionmaking. This report specifically stated, "The legal system has various—though limited—roles in ensuring that seriously ill infants receive the correct care."⁹ One such role is served by the civil courts that consider cases in which the parents may not appropriately represent the best interests of the child and appoint an appropriate surrogate. The commission also supported the role of the state for investigation of suspected child neglect or abuse but decried "using financial sanctions against institutions to punish an 'incorrect' decision in a particular case," doubting the usefulness and pointing out that such action might "actually penalize other patients and providers in an unjust way."⁹ This last statement was a direct rebuke of the contemporaneous impending formulation of the Baby Doe rules conceived under CAPTA and enforceable only by withholding federal funding for anti-child abuse programs.

THE INFANT ETHICS COMMITTEE

The American Academy of Pediatrics (AAP), which organized the Infant Bioethics Task Force and Consultants to consider the ethics of neonatal care, also supported the tradition of the best interests standard. Recognizing the contemporary controversy and following the arguments from the President's Commission, as well as making an effort to influence the federal regulations still under review, the task force issued the Guidelines for Infant Bioethics Committees.¹⁰ In this document, clearly directed at minimizing the effect of federal regulatory efforts and supporting the President's Commission, the AAP recommended that "each hospital that provides care for infants give serious consideration to the role an Infant Bioethics Committee may play in aiding decisionmaking about the care of seriously ill infants."¹⁰ Furthermore, the AAP specifically identified one of the functions of the committee as "offering consultation and review on treatment decisions regarding critically ill infants, especially when the foregoing of life sustaining treatment is being considered."¹⁰ The guidelines promoted both prospective review of all cases in which questions arise

and retrospective review of all cases in which a decision is made to withdraw support.

Although most of the AAP statement was simply a proposal for how such committees should function, it was also an effort to document a consistent approach to end-of-life decisions in the withdrawal of support for infants (defined in this document as those under 2 years of age). In a nod to the Reagan administration's then-impending regulatory efforts, the statement emphasized the legal responsibilities for reporting suspected instances of child neglect or abuse. Recognizing the volatile contemporaneous legal environment, the statement also pointed out the importance of indemnification for committee members to protect them from potential legal action.

CONFLICTING STANDARDS

Recommendations for making surrogate decisions using the best interests standard are clearly outside the realm of considerations acceptable under the 3 specific guidelines in the Baby Doe rules.⁵ The rule utilitarian approach advanced by the Baby Doe rules—driven by the belief that life is preeminent and no other considerations are pertinent—conflicts directly with the approach of the best interests standard cited by the President's Commission and endorsed by the AAP. This conflict has placed pediatricians, neonatologists, and others providing care for newborn infants in the position of choosing to follow either federal rules that appear unequivocal or the guidance of the AAP and tradition in upholding the best interests standard.

The conflict is further complicated by the stand of the AAP, which maintains that the best interests standard can be reconciled with the Baby Doe rules based on a very liberal and, most would argue, incorrect interpretation of the phrase "...when, in the treating physician's (or physicians') reasonable medical judgment...." The AAP contends that this phrase allows broad discretion in deciding which infants might fall into the 3 categories exempted from the rules, thus supporting the best interests standard as the basis for decisionmaking in almost all circumstances. This debate fills the literature because the rules were promulgated primarily by federal guidance documents interpreting the rules. In addition, a large body of literature attempts to reconcile the apparent inflexibility of the Baby Doe rules with the widely held tradition of acting in the best interests of the infant based on careful consideration by the family and other caretakers.

Continuing to support the best interests standard and maintaining that it does not conflict with the Baby Doe rules, the AAP again addressed end-of-life issues for children in "Guidelines on Foregoing Life-Sustaining

Medical Treatment,”¹¹ reiterating the general views about parental decisionmaking outlined by the President’s Commission. This statement addressed the unique constraints imposed by the Baby Doe rules but deferred discussion of decisions made for neonates to a later document, “The Initiation or Withdrawal of Treatment for High Risk Newborns,” written by the Committee on the Fetus and Newborn.¹² This distinction reflects the unique approach to decisionmaking necessitated in this population by the special nature of Baby Doe rules that only apply to infants under 1 year of age. The opening statement confirmed the AAP’s position: “Medical treatment of infants should be based on what is in their best interest.” But the document acknowledged that infants’ best interests may be difficult to discern.¹² The paper noted that the particular dilemma posed by this age group probably led to the schism between the rule utilitarian approach of the Baby Doe rules and guidelines supporting the best interests of the child. The paradox is that without support, many of the infants would die or suffer significant morbidity, but with support many would suffer catastrophic disabilities or a prolonged death. “The overall outcomes of either approach are disappointing.”¹²

Following the Baby Doe rules means that all except those imminently faced with death will be supported, thus assuring that no child who potentially could survive would die as the result of a decisionmaker’s choice for no intervention. The cost of this utilitarian stand is that many infants could die slowly or suffer what many would feel to be unbearable disabilities to assure that no potential survivor dies because parental decisionmaking was allowed. Those supporting the best interests standard suggest that the family is best able to make choices for the infant, taking into account their family values and which set of risks is most appropriate for their child. The report emphasized the importance of communication with decisionmakers, supporting the concept of complete and accurate information as essential elements for good decisions, as suggested by the President’s Commission.

The AAP policy was updated in 2007 after new members reviewed the previous recommendations. This new committee reaffirmed the best interests standard as the appropriate basis for neonatal decisions.¹³ The document reviewed the difficulty of providing an accurate prognosis for critically ill infants, and the policy supported the role of parents in decisionmaking. Further clarifying this position and paraphrasing the recommendations from the President’s Commission in 1983, this policy statement supported foregoing intensive care in cases that are likely fatal or have a high risk for severe morbidity and

always providing intensive care when the outcome is very likely to be survival with low risk for severe morbidity. The policy deferred to parental decisionmaking based on the best interests standard only in cases where “the prognosis is uncertain but likely to be very poor and survival may be associated with a diminished quality of life for the child.”¹³ These standards should apply throughout the treatment of the infant with a recommendation for constant reappraisal of the infant’s status.

FRAMING THE CONTROVERSY

Also in 2007, the AAP awarded the William G. Bartholome Award for Ethical Excellence to Loretta Kopelman, PhD, for her work in pediatric ethical issues. A vocal advocate of the best interests standard throughout her career, she chose a defense of the best interests standard for neonatal care as the topic of her acceptance speech.¹⁴ Kopelman called on the AAP to withdraw its conflicted support of the Baby Doe rules in favor of fully supporting the best interests standard. Her argument included the observation that the official stance of the AAP—that the Baby Doe rules are compatible with the best interests standard—sprang from the misconception that the inclusion of reasonable medical judgment in the regulations can be interpreted as it was by the president of the AAP at the time the rules were promulgated. While the rules were in formulation, the AAP president stated: “It would appear that the final rule reaffirms the role of reasonable medical judgment and that decisions should be made in the best interests of infants.”¹⁵ This interpretation is clearly not the intent of the statement in the Baby Doe rules that allows the exercise of “reasonable medical judgment” only in the 3 explicit circumstances when lifesaving treatment is not required.⁵

Kopelman reviewed the medical tradition of supporting the best interests standard, as well as the powerful arguments in support of this concept from bioethics panels appointed by Reagan and later by George W. Bush (both presidents advocated support of the Baby Doe rules). She argued that standing by the best interests standard for surrogate decisionmaking for everyone except children under the age of 1 year as specified in the Baby Doe rules is unwarranted. Kopelman said she could find no moral difference between the aged who may be unable to make their own decisions and newborn infants. If the best interests standard fulfills “three necessary and jointly sufficient conditions,” she noted, “the Best Interests Standard should be adopted as the only guidance principle for minors and incapacitated and incompetent adults without preferences or advance directives.”¹⁵

Throughout the history of this conflict, there has been little examination of the extent to which society supports the Baby Doe rules. The ethics literature and the legal literature have most often argued against the rigidity of the Baby Doe rules as written. On the opposite side of the argument, attempts have been made, particularly during conservative administrations, to strengthen the regulatory applicability of the Baby Doe rules and generalize them from just those infants with handicaps to infants born at the threshold of viability.

Most recently, this goal has been supported by an interpretation that would apply the provisions of the Born Alive Infant Protection Act and the Emergency Medical Treatment and Labor Act (EMTALA) as means of more punitive enforcement. Dr Sadeth Sayeed¹⁶ summarized these efforts, reviewed the directives from various arms of HHS in 2005, and presented concerns that the normative ethical practices of decisionmaking following the best interests standard endorsed by the AAP were at risk by HHS's interpretation at that time. Specifically, Sayeed cited guidance documents interpreting the delivery room as a potential emergency department with the threat of legal action by federal agencies and by any individual who might be harmed under the EMTALA regulations.¹⁶ To date, no such allegations have been investigated, but the documents and directives survive.

During all these deliberations to decide how best to make decisions for infants, the overwhelming normative practice in neonatal medicine has been to follow the best interests standard, but the legality of this practice looms over the neonatal intensive care unit. However, in nearly 30 years of deliberations about the Baby Doe case and the legal activity prompted by the medical decisions made for that infant, only one case cites the Baby Doe rules.

In a letter to the editor of *Pediatrics*, Clark¹⁷ reviewed the case of *Montalvo v Borkovec*, in which a family brought action alleging that their very premature infant was resuscitated against their wishes. They claimed that discussion of the prognosis was inadequate and that they did not consent to any treatment that would allow the physicians to proceed with resuscitation. The court ruled that under Wisconsin law informed consent was not necessary in this circumstance. The court supported this ruling by citing the Baby Doe regulations, with the opinion that withholding life-sustaining efforts was not a legal alternative because the child was not in a persistent vegetative state. Because the state of Wisconsin accepts federal funds for CAPTA, the Baby Doe regulations must be followed, the court noted. It is noteworthy that this case presents the only citation of the Baby Doe rules as legal precedent, before or

since. Additionally, the case was not brought under the intended application of the Baby Doe rules as an action of child protective services. The Baby Doe rules were used to support a court decision that could stand on its own merits under Wisconsin law. Clark concluded that "discussion of Baby Doe was gratuitous and not necessary to the decision in the case."¹⁷

THE DILEMMA: WHERE ETHICS AND LAW DIVERGE

All of this history simply outlines the dilemma faced by those providing care for neonatal patients. It is clear that the Baby Doe rules and normative ethics do not concur regarding decisionmaking. Must one follow the law, which is very specific but has no history of enforcement and, by inference, is not the standard of care? The possibility that these rules would be legally problematic was foreshadowed by remarks early in the history of this debate. A review of the Baby Doe rulings in 1986 presented the controversy as it existed when the rules were formulated.¹⁸ The authors made the case that controversial laws created without widespread acceptance have an unpredictable course and "citizens will find other ways to preserve choices they think they ought to have." Citing the likely unintended consequences of these rules, which include survival of infants with marginal health, Huefner concluded: "If the government demonstrates its genuine concern for the early and continuing stimulation of the infant's development, perhaps a more integrated government role can emerge—one that will better balance the legitimate interests of the child, the parents, the medical community, and society."¹⁸

The predicted unintended results were borne out in a later review that cited many of the historically difficult positions brought about by concern that the Baby Doe rules might be enforced.¹⁹ This critique formulated 3 arguments opposing these rules. First, the rules address a problem that does not exist except in exceptional circumstances (a position frequently encountered in discussion of the Baby Doe rules). Second, a uniform federal standard oversimplifies the complex moral and ethical decisions presented by critically ill neonates. Third, the policy simply fails to follow intuition by excluding parents from any decision-making capacity in contrast to well-established legal tradition.¹⁹ The policy erroneously assumes that a decision in favor of life is always in the infant's best interest, the critique noted, and this assumption conflicts with the normative ethic that quality of life contributes significantly to ethical decisionmaking. The article pointed out the general acceptance of quality of life as a factor: "The truth is that nearly all of us, the proponents of the federal policy included, hold such

issues to be important in our daily lives.”¹⁹ After presenting the case against the Baby Doe rules, the authors called to eliminate the federal role in treatment decisions and to support decisionmaking by parents in consultation with the physicians caring for the child. The authors concluded that the approach “should not be swept aside with simplistic social policy that overlooks the profound ethical, medical, and legal questions that such situations pose.”¹⁹

Where does all of this controversy leave those who daily make decisions for critically ill newborns? The AAP guidance is clear in its recommendation that the day-to-day decision-making process in almost all circumstances remains in the domain of the family and caretakers, with the normative practice to follow the best interests standard. The AAP acknowledges that the Baby Doe rules exist but maintains that the inclusion of “in the treating physician’s (or physicians’) reasonable medical judgment” accommodates the normative practice.⁵ When law and practice conflict, actions in the courts usually provide guidance. The lack of legal case history to dispel the interpretation of the AAP might be viewed as tacit approval for this interpretation, but the possibility of enforcement continues to exist as long as the rules remain in place.

WHAT TO DO?

This long history of controversy begs for resolution, and when questions arise, the role of the hospital ethics committee is critical to the appropriate resolution. Few hospitals providing neonatal intensive care and fewer community hospitals have active infant ethics committees as proposed in the 1984 recommendations of the AAP.¹⁰ The Joint Commission on Accreditation of Healthcare Organizations (now known as The Joint Commission) mandates a process for addressing ethical concerns with wide latitude regarding the mechanism for meeting this requirement. Little evidence suggests that reviewing neonatal decision-making, as envisioned by the AAP and the President’s Commission, is commonly considered part of this process. Furthermore, no evidence demonstrates that a standard of care or consensus exists for the ongoing review of decisions made to forego life-sustaining treatment for neonates in any forum.

How then should we proceed to ensure that appropriate decisions are made for these vulnerable patients? We might ask, despite all the controversy in the literature, if the problem really exists. Although a great deal of literature discusses the disparate viewpoints of the Baby Doe rules and the best interests alternative, cases questioning the decisions made are quite rare. This fact is supported by the dearth of legal cases citing the Baby Doe regulations; also, no state

has lost federal funds for failure to comply with CAPTA. Infant ethics committees are not readily apparent, and no literature documents regular review of decisions to withhold life-sustaining treatment.

It seems that the best approach is to be prepared to address concerns as they arise. When questions are posed concerning the management of a newborn infant, the questions should be addressed through the process mandated by The Joint Commission. In most instances, this process entails a hospital ethics committee. It is incumbent on those serving in this advisory capacity to understand both the history and the controversy surrounding neonatal decisions for life-sustaining treatments. Any recommendations must consider the specific requirements of the Baby Doe regulations and, according to what appears to be the *de facto* standard of care, the requirements for the best interests standard. This process should begin by considering the goals of infant ethics committee reviews suggested by the President’s Commission in 1983:

First, verify that the best information available is being used.

Second, confirm the propriety of a decision that providers and parents have reached or confirm that the range of discretion accorded to the parents is appropriate.

Third, resolve disputes among those involved in a decision, by improving communication and understanding among them and, if necessary, by siding with one party or another in a dispute.

Finally, refer cases to public agencies (child protection services, probate courts, or prosecuting attorneys) when appropriate.⁸

This process, if carried out with consideration of the suggested goals, should ensure that the best possible decisions are made for newborn infants. Recognizing that these circumstances are difficult for all parties involved, the President’s Commission believes that this process “has the potential both to guarantee a discussion of the issues with a concerned and disinterested ‘representative of the public’ and to insulate these agonizing, tragic decisions from the glare of publicity and the distortions of public posturing that commonly attend court proceedings.”⁸

This statement has proven prescient in light of the very public controversy surrounding the death of Terri Schiavo. The potential to propagate controversy via television, internet, Twitter, and personal blogs was demonstrated in the hijacking of what should have been very private deliberations to serve as a platform for the political and private interests of many others

beyond the patient and her family. In light of the controversy surrounding decisions at the beginning of life, the potential for such trials by media always looms over what should be private decisions. We can only hope that careful, knowledgeable consideration following the tenets of the best interests standard when such cases present will result in gentle resolution of the concerns in a private way.

REFERENCES

1. National Library of Medicine. The C. Everett Koop papers: Congenital birth defects and the medical rights of children: the "Baby Doe" controversy. <http://profiles.nlm.nih.gov/ps/retrieve/Narrative/qq/p-nid/86>. Accessed July 6, 2011.
2. 504. 47 Fed. Reg. 26027 (1982).
3. 48 Fed. Reg. 9630 (1983).
4. Annas GJ. The case of Baby Jane Doe: child abuse or unlawful Federal intervention? *Am J Public Health*. 1984;74(7):727-729.
5. 45 CFR 1340.15 Services and treatment for disabled infants.
6. Robertson JA. Extreme prematurity and parental rights after Baby Doe. *Hastings Cent Rep*. 2004;34(4):32-39.
7. American Medical Association Judicial Council. Current opinions of the Judicial Council of the American Medical Association. Chicago: American Medical Association; 1981.
8. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. Making health care decisions: a report on the ethical and legal implications of informed consent in the patient practitioner relationship. October 1982. http://bioethics.georgetown.edu/pcbe/reports/past_commissions/making_health_care_decisions.pdf. Accessed July 6, 2011.
9. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. Deciding to forego life-sustaining treatment: a report on the ethical, medical, and legal issues in treatment decisions. October 1983. http://bioethics.georgetown.edu/pcbe/reports/past_commissions/deciding_to_forego_tx.pdf. Accessed July 6, 2011.
10. American Academy of Pediatrics Infant Bioethics Task Force and Consultants. Guidelines for infant bioethics committees. *Pediatrics*. 1984;74(2):306-310.
11. American Academy of Pediatrics Committee on Bioethics. Guidelines on foregoing life-sustaining medical treatment. *Pediatrics*. 1994;93(3):532-536.
12. American Academy of Pediatrics Committee on Fetus and Newborn. The initiation or withdrawal of treatment for high-risk newborns. *Pediatrics*. 1995;96(2 Pt 1):362-363.
13. American Academy of Pediatrics Committee on Fetus and Newborn, Bell EF. Noninitiation or withdrawal of intensive care for high-risk newborns. *Pediatrics*. 2007;119(2):401-403.
14. Kopelman LM. A new analysis of the best interests standard and its crucial role in pediatric practice. Address at the 2007 AAP National Conference and Exhibition Section on Bioethics Program, San Francisco, CA. <http://www.aap.org/sections/bioethics/PDFs/KopelmanSpeech2007.pdf>. Accessed July 6, 2011.
15. Murray TH. The final, anticlimactic rule on Baby Doe. *Hastings Cent Rep*. 1985;15(3):5-9.
16. Sayeed SA. Baby Doe redux? The Department of Health and Human Services and the Born-Alive Infants Protection Act of 2002: a cautionary note on normative neonatal practice. *Pediatrics*. 2005;116(4):e576-e585.
17. Hurst I. Baby Doe rules. *Pediatrics*. 2005;116(6):1600-1601; discussion 1601-1603.
18. Huefner DS. Severely handicapped infants with life-threatening conditions: federal intrusions into the decision not to treat. *Am J Law Med*. 1986;12(2):171-205.
19. 34 New Eng L Rev 343 (1999-2000).

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